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Couples' Coping in Prodromal Huntington Disease: A Mixed Methods Study

Nancy R. Downing¹, Janet K. Williams¹, Anne L. Leserman², and Jane S. Paulsen^{2,*}

¹The University of Iowa College of Nursing, Iowa City, IA 52242, USA

²The University of Iowa Carver College of Medicine, Iowa City, IA 52242, USA

Abstract

Huntington disease (HD) includes a prodromal phase with behavioral, cognitive, and motor function decline occurring up to 15 years prior to diagnosis. This study used mixed methods to examine how people with prodromal HD and their companions coped with noticed changes. Twenty-three couples completed a semi-structured interview and Brief COPE. Participants with prodromal HD used acceptance, emotional support, and planning most frequently; companions used acceptance, planning, and active coping. Least frequently used coping strategies for each were denial, behavioral disengagement, and substance use. Qualitative interviews revealed coping strategies not included in the Brief COPE. Participants with prodromal HD used prescription medications, coping as a couple, hope, and self-monitoring; companions used hope and helping their partners. Many of the coping procedures were rated as effective, especially when changes were not severe. Couples may benefit from prodromal HD counseling that emphasizes using active coping strategies for changes that can be compensated for and acceptance for changes that cannot. Findings from this study may be helpful for counseling patients and significant others facing other neurodegenerative conditions with prodromal or early phases, such as Alzheimer disease and Parkinson disease.

Keywords

Huntington Disease; coping; genetic counseling

Introduction

Huntington disease (HD) is a progressive neurological disease that involves declining behavioral, cognitive, and motor function and premature death. It is caused by an expanded trinucleotide (CAG) repeat on chromosome 4 and has a dominant inheritance pattern—people with an affected parent have a 50% chance of developing the disease (Walker, 2007). Average age of diagnosis is between 35 and 55 (Quarrell, 2008) and is based on the presence of distinctive motor signs—chorea, dystonia, and impaired voluntary movements (Hogarth, 2003). Changes in brain structure, cognition, and motor function can be detected in people with the HD gene expansion up to 15 years before diagnosis (Paulsen, 2010). Little is known regarding how people who have tested positive for the HD gene expansion and their companions cope with functional changes before diagnosis, a period that has been referred to as prodromal HD (Paulsen, 2010).

*Correspondence to: Jane S. Paulsen PhD, The University of Iowa Carver College of Medicine, Research, 1-305 Medical Education Building, Iowa City, IA 52242-1000; 319-353-4551 (PHONE); 319-353-3003 (FAX); jane-paulsen@uiowa.edu.

People with prodromal HD and their family members have noticed functional changes, but they didn't necessarily attribute them to HD (Downing, Williams, & Paulsen, 2010). Family members have also reported irritability, impaired judgment, difficulty sleeping, and problems with balance, but expressed uncertainty regarding whether changes were related to HD (Williams et al., 2007). They also expressed a desire for more information regarding what to expect prior to diagnosis. Less is known regarding how people with prodromal HD and their family members cope with these changes.

Coping has been defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). The ways people cope is important to quality of life because it impacts their mental and physical health (Lazarus & Folkman, 1984). Problem-focused coping involves cognitive processes such as obtaining information and forming action plans; emotion-focused coping involves addressing emotional responses to threats while not altering the threats themselves (Lazarus, 1999). There may be gender differences with regard to coping; women may use more emotion-focused coping and men more problem-focused coping (Tamres, Janicki, & Helgeson, 2002).

Coping with illness is rarely a solitary process. When one partner in a couple is affected by illness, the other partner is also affected (Kenny & Cook, 1999). Coping in couples can be characterized by congruence or complementarity (Badr, 2004). With congruent coping, members of a couple use similar coping strategies. In some instances, congruence has been associated with more favorable outcomes (Pakenham, 1998). Complementarity, on the other hand, is the recognition that it is not necessary for both members of a couple to cope in the same way in order to cope effectively (Badr, 2004; Ben-Zur, Gilbar, & Lev, 2001).

While there are no studies that examine coping with functional changes in prodromal HD, Helder and colleagues (Helder, et al., 2002b) explored coping in 90 spouses of people with diagnosed HD. The most commonly used coping strategies by spouses (54% female) using the COPE scale (Carver, Scheier, & Weintraub, 1989) were acceptance, positive reinterpretation and growth, active coping, and planning. In a qualitative exploration of coping in ten HD caregivers (60% female), avoidance of thinking or talking about HD was the primary theme (Lowit & van Teijlingen, 2005).

The purpose of this study was to use qualitative and quantitative methods to describe coping by people with prodromal HD and their companions. The research questions included: 1) How do people with prodromal HD and their companions cope with perceived functional changes in prodromal HD? 2) Do people with prodromal HD and companions use similar or different coping strategies? 3) Are the coping strategies effective? 4) Are coping strategies different for those who attribute changes to HD? 5) Is there a correlation between frequency of coping strategy use and number of changes attributed to HD? Genetic counselors and therapists who see people considering genetic testing for the HD mutation may find this information about coping techniques useful in their assessments. The population of at-risk HD people that consider testing may have ways of coping with prodromal HD that are unique.

Materials and Methods

This study used a mixed methods design. The theoretical thrust of the study purpose was inductive; thus the core component of this study was qualitative (Morse & Niehaus, 2009), while the quantitative component facilitated systematic assessment of coping, and comparison of coping strategies between people with prodromal HD and companions.

Potential participants were identified in collaboration with a coordinator of the PREDICT-HD study, a multi-site longitudinal study designed to identify and track markers of HD during the prodromal period (Paulsen, 2010). Purposeful criterion sampling identified participants who were likely to provide rich information (Patton, 2002). Inclusion criteria included: people with prodromal HD estimated to be 15 years from HD diagnosis using an algorithm based on CAG length and current age (Langbehn et al., 2004), 21 years old, and English-speaking. Each person with prodromal HD had to have a spouse or significant other who was also willing to participate. Couples were excluded if the companion had a severe chronic health condition. The study was approved by The University of Iowa Institutional Review Board. Prospective participants were contacted by telephone or by mail.

Demographic information collected prior to the semi-structured interviews included age, gender, whether participants with prodromal HD had children, and how long companions had known their partners. A semi-structured interview guide asked how the person with prodromal HD was functioning, and whether participants noticed any changes in any of the following areas of function: work, home, relationships, social life, physical activities, driving, planning, memory, and performing new tasks. Items came from functional changes previously endorsed by people with prodromal HD and their family members (Downing et al., 2010; Williams et al., 2007) as well as changes identified by researchers in a clinical setting (Paulsen, 2010). Participants were asked what strategies they used to cope with any functional changes they reported and whether they considered their coping strategies to be effective. Companions were asked how they coped with their partners' changes. See Table 1 for sample interview questions.

The Brief COPE (Carver, 1997) consists of 28 questions, with two questions for each of 14 scales: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. Internal reliability for each Brief COPE scale range from .57 (acceptance) to .90 (substance use) (Carver, 1997). Participants rate items based on how frequently they have used each coping strategy: A score of "1" equals "I haven't been doing this at all;" and "4" equals "I've been doing this a lot." Since the measure was orally administered, "I" statements were changed to "you" statements. The Brief COPE has been used by researchers to assess coping with a variety of illnesses, including perinatal depression (de Tyche et al., 2005), cystic fibrosis (Wong & Heriot, 2008), and mental illness (Meyer, 2001).

Interviews were audio-recorded using a digital audio recorder and transcribed verbatim, removing identifying information. Transcripts were imported into NVivo8 (QSR International, 2007) for qualitative data management. Quantitative data were managed using Excel spreadsheets and PASW Statistics Developer (SPSS, 2009).

The Brief COPE was not intended to generate a composite coping score (Carver, 2007). However, higher scores on the Brief COPE indicate more frequent use of coping strategies, which conceptually could indicate greater perception of demands under Lazarus' definition of coping. Therefore, mean total scores on the Brief COPE were calculated to indicate how frequently participants used coping procedures. Mean coping for the entire scale and for each of the 14 two-item coping strategies were averaged to retain the 1–4 range.

A dependent *t*-test was used to compare differences in frequency of coping and types of coping strategies used between participants with prodromal HD and companions. Independent *t*-tests were used to compare differences in coping frequency by gender and between participants who attributed changes to HD and those who did not. Effect sizes were calculated using Cohen's *d*. Pearson correlation coefficients were used to test for congruence

of coping strategies between participants with prodromal HD and companions and to test for correlation between frequency of coping and number of changes attributed to HD.

Data were analyzed using descriptive interpretive methodology (Thorne, Kirkham, & MacDonald-Emes, 1997). Transcripts were coded by two researchers using coping strategies from the Brief COPE as an initial coding frame. If researchers identified coping strategies not in the Brief COPE they created additional codes. The researchers identified major themes from the descriptive codes and discussed all coding until they reached 100% agreement to establish descriptive and interpretive validity (Sandelowski, 2000).

Summative content analysis (Hsieh & Shannon, 2005) of the qualitative data facilitated comparison with quantitative results. The purpose was to compare coping strategies between the Brief COPE and interview data. This provided insight into the ability of the Brief COPE to comprehensively capture coping strategies in prodromal HD. A Brief COPE strategy was scored as used if participants indicated that they used it at least a “little bit” (a score of 2 or higher).

Results

Twenty-three couples participated after inviting 99 people with prodromal HD to participate. The most common reasons for declining were not having a significant other, or having a significant other who did not want to participate. Although data saturation was reached after interviewing 15 couples, all interested couples were interviewed in order to add richness to the qualitative data and facilitate meaningful interpretation of quantitative data.

The majority of participants with prodromal HD were female (N=17; 73.9%), and 69.6% of companions were male (N=16). Most couples were married (N=21; 91.3%); two were committed partners. Mean age of participants was 48.96 (SD=11.80; range 33–78); mean age of companions was 49.96 (SD=10.47; range 31–67). Couples had known each other a mean of 22.46 years (SD=13.32; range=0.5–47 years; median=21 years). Two participants with prodromal HD did not have children.

Means and standard deviations for three most and least frequently used Brief COPE items are presented in Table 2. The three most frequently used coping strategies endorsed by all participants on the Brief COPE were acceptance, planning, and emotional support. Participants with prodromal HD used coping strategies more frequently than companions ($t=3.11$; $p < .01$; $d=.81$). Participants with prodromal HD had a mean total score on the Brief COPE of 2.26 (SD=0.43); companions had a mean total score of 1.91 (SD=0.44). Females used coping strategies more frequently than males ($t=3.21$; $p < .01$; $d=.76$). The number and percentage of participants who endorsed using each strategy at least “a little bit” are listed in Table 3.

Significant differences in frequency of coping strategies used by participants with prodromal HD and companions included: self-distraction ($t=2.79$; $p=.01$; $d=.84$); emotional support ($t=4.24$; $p=.00$; $d=1.28$); instrumental support ($t=2.26$; $p=.03$; $d=.68$); and self-blame ($t=2.21$; $p=.04$; $d=.68$). In all cases, participants with prodromal HD used these coping strategies more frequently than companions. However, while more participants with prodromal HD used self-blame and self-distraction, they used them infrequently. Couples were congruent in their use of three coping strategies: active coping ($r=0.46$; $p<.03$); planning ($r=0.45$; $p<.03$); and religion ($r=0.51$; $p<.02$). The correlation between number of HD attributions for changes and frequency of coping strategies was not significant. Frequency of Brief COPE coping strategies was not related to making HD attributions ($p=.12$).

Qualitative Analysis Results

Interviews lasted an average of 29 minutes for participants with prodromal HD (range 9–58) and 25 minutes for companions (range 13–48). Most couples (N=13) were congruent in reporting no HD-related changes and four couples were congruent in their endorsement of HD-related changes. Three participants with prodromal HD and three companions attributed changes to HD when their partners did not. Participants attributed changes most often to age, temperament, and other stressors.

While most participants did not attribute changes to HD, most did notice changes. The most common changes mentioned by both participants with prodromal HD and companions were: physical changes (tired, slowing down, fidgeting, and dropping things); short-term memory problems; mood changes and irritability; work stress and employment changes; cognitive changes (difficulty focusing and finishing tasks, apathy, and difficulty with math); relationship issues; driving issues; decreased socializing; difficulty planning; and performing new tasks.

Coping strategies did not differ according to whether participants attributed changes to HD or not. Instead, strategies were directed toward specific stressors regardless of the attributions. For example, it didn't matter whether participants with prodromal HD attributed memory problems to HD or to aging; they coped mostly by using memory aids. Participants with prodromal HD who attributed changes to HD used avoidance strategies, such as social withdrawal or not doing tasks that were problematic like driving or doing new things. Companions who attributed changes to HD used more coping strategies than companions who didn't notice changes or attributed changes to things such as aging or temperament. Companions who attributed changes to HD used active coping strategies for things they thought they could fix, and acceptance or distraction for those they couldn't. In the interpretive analysis, the researchers identified three major themes related to coping with changes: *Trying to Fix It*, *Can't Fix It*, and *Not Broken Yet*.

Trying to Fix It—The most common theme related to trying to fix changes that interfered with functioning. Participants with prodromal HD described actions they took to try to fix changes: using memory aids; taking prescription medications; working on relationships; seeking advice, assistance, or information; making plans for the future; and self-monitoring. Examples include: “I’ve been trying to find some type of work that works for my brain that I can still do” [P15]; “I have a hard time making connections with people I’m trying to go out of my comfort zone and do those things more now” [P06]; “[I] don’t drive with the radio on ... I pay very [good] attention to all the things because I don’t drive a lot” [P04].

Companions described actions they took to try to fix changes, including responding to partners’ irritability, helping their partners, planning for the future, and seeking information and advice: “I push her as much as I can to exercise because I know that that’s gonna be critical when she does get onset” [C05]; “I pay all the bills because she’s not good at that anymore” [C18]; “[W]e just try to help her out” [C18].

Can't Fix It—Some participants did not try to fix things. These coping strategies fell into two major categories: participants who had tried and given up when strategies were not working; and participants who stated there were some things that couldn't be fixed. Participants with prodromal HD who coped by giving up or avoiding situations that were problematic used distractions, humor, or accepting things they couldn't fix: “I just pray, and I try to put it out of my mind and go on” [P04]; “You know, if it’s something new, I’ll avoid it” [P15]; “[S]ome things I don’t feel like I can do anymore” [P04]; “I have just become more accident prone, you know, drop stuff ... I’ve pretty much accepted that it’s going to happen” [P06].

Companions who stated they couldn't fix some things coped by giving up, avoiding stressors, using distractions, or accepting: "I've learned the things *not* to do ... [I] definitely don't try to fix it" [C12]; "Our sex life sucks ... I experience being depressed a lot. I mean that's my way of coping" [C15]; "I just go on with my life" [C07]; "[E]ssentially, coping is taking your mind off of [things], looking at things on the internet, reading" [C20].

Not Broken Yet—Participants who didn't notice changes or who stated changes were not severe stated they did not need to use any coping strategies: "In my head ... I'm only carrying the gene [mutation]; it [has] not come into my lifestyle yet" [P22]; "Every now and then I'll forget [to do something] ... I guess it doesn't worry me excessively. I just try to keep track of [it]" [P05];

Companions who stated there were no changes yet expressed that they didn't need to cope yet: "The situation isn't bad, so I don't feel the need to resolve anything" [C02]; "The only thing we have to deal with is that he has [the gene mutation]. Thank goodness we don't have to deal with symptoms also right now" [C07].

Mixed Methods Analysis Results

Combined quantitative and qualitative data analysis identified the three most commonly used coping strategies as: active coping, instrumental support, and use of prescription drugs (Table 2). In side-by-side comparisons, participants with prodromal HD described all of the coping strategies included on the Brief COPE during interviews except denial and self-blame. While participants with prodromal HD endorsed using emotional social support on the Brief COPE, they rarely talked about emotional support in interviews. Four coping strategies mentioned by participants with prodromal HD that are not on the Brief COPE were: use of prescription drugs, coping as a couple, self-monitoring, and hope. They used prescription medications to treat depression, anxiety, sleep problems, and distractibility. In all cases, participants using prescription drugs stated they were effective. Coping as a couple refers to talking about changes together and seeking help as a couple: "Well, normally when I notice stuff or my husband notices stuff, we talk it out ... [H]e'll say, 'I notice this and I notice that. What do you think?'" [P06]; "[W]e really help each other in a lot of areas, you know. We assist each other and, you know, pay attention to each other's things" [P15].

Participants with prodromal HD self-monitored for changes or used hope as strategies to control them better: "I truly feel anger ... So I have a little bit of concern there ... And I will watch it" [P01]; "I'm starting to pay attention to my body and noticing things" [P12]; "I'm hoping that if I really start not being this normal guy that I've always been ... hopefully I'll be able to grasp it before it's too late" [P07]; "[T]he other thing that has given me a lot of hope and encouragement is there's also been a lot of things on brain plasticity ... I can have some control over how I train my brain" [P12].

The most commonly used coping strategies described by companions in the interviews were active coping, acceptance, and helping partners. Hope was a coping strategy mentioned in interviews that was not on the Brief COPE. A companion hoped his partner would "make it" until she was able to qualify for full insurance benefits [C19].

In the interviews, participants with prodromal HD described using more coping strategies than companions, which is consistent with the Brief COPE results. While participants with prodromal HD used self-monitoring to anticipate and control problems, a minority view expressed by companions was concern that their partners focused on HD too much, which inhibited them from leading normal lives:

[T]here appears to me to be no symptoms ... but she sees them starting to manifest." ... [T]o her ... it just feels like her clock is ticking... . And ... that to me ... is what is robbing her of her joy and her quality of life [C04].

Discussion

The total mean scores on the Brief COPE for both participants with prodromal HD and companions were low, which indicates that participants did not use these coping procedures often. This may reflect that they did not need to cope often or they used coping strategies that were not on the Brief COPE. The qualitative findings support the former since the majority of participants stated they had very little to cope with, and participants used only a few coping strategies that were not on the Brief COPE. Lazarus and Folkman's (1984) conceptualization of coping as an imbalance between demands and resources suggests demands were not currently exceeding resources. However, some participants noticed changes and were using more coping strategies, indicating coping may change as people move nearer to the time of diagnosis.

The three most frequently used coping strategies in this study are similar to those used by people with diagnosed HD and their spouses using the COPE scale (Helder et al., 2002a; Helder et al., 2002b). One difference in the current study is that participants with prodromal HD used emotional support as one of the top three coping strategies as reported on the Brief COPE, but did not talk about seeking emotional support in the interviews. This suggests that either research participants are more likely to endorse things they are probed to endorse, or that the interview responses focused on coping with functional changes, which may lead to a bias toward action-focused coping.

Most participants noticed subtle changes but attributed them to aging, temperament, and other stressors, which is consistent with previous findings (Downing et al., 2010). This is also consistent with coping literature that states people attribute subtle and ambiguous changes to benign conditions and wait until symptoms are severe and distinctive before attributing them to illness (Leventhal, Leventhal, & Contrada, 1998). Mean age of participants with prodromal HD in this study (48.96; SD=11.8) was close to 49. Therefore, it was not surprising that some participants attributed subtle changes such as memory problems to aging. On the other hand, given that the average age of onset of HD is between 35–55 (Quarrell, 2008), it was equally surprising that more participants did not attribute at least some changes to HD.

The low incidence of HD attributions might indicate participants used denial as a coping strategy, despite denial being one of the least used coping strategies endorsed by participants on the Brief COPE. However, since denial is considered an unconscious defense mechanism (Cramer, 2000), it is questionable whether participants would endorse it. Participants in studies of other illnesses also reported low use of denial and high use of acceptance (de Tyche et al., 2005; Lewellyn, McGurk, & Weinman, 2007; Vosvick et al., 2003).

The most frequently used coping strategy endorsed by both participants with prodromal HD and companions was acceptance. Because participants with prodromal HD in this study had independently obtained HD testing and participated in HD-related research, they may be more representative of those who have accepted their condition. Thus, the tendency for participants to attribute changes to things other than HD in the interviews is notable. While many of the changes noticed by participants were subtle, many of them may be related to HD (Biglan et al., 2009; Duff et al., 2010; Paulsen, 2010; Stout et al., 2011; Tabrizi et al., 2011).

Denial is not necessarily a negative coping strategy; it can be helpful in coping with an illness that is severe and has a poor prognosis (Lazarus, 1999). Another way to characterize denial as a positive coping strategy is to view it as normalization (Deatrck, Knafel, & Murphy-Moore, 1999), which occurs when people living with chronic illness attempt to construct their lives as normal (Robinson, 1993). While this can have a positive effect by allowing people with chronic illnesses to experience life as normal, it can have negative consequences if people minimize problems to the extent that they fail to take action when it might be beneficial. It is possible that if people with prodromal HD and their companions normalize life too much, they may not adequately plan for the future or fail to notice changes that might have important consequences. For example, people who grew up in families with HD-affected parents reported high rates of family dysfunction (Vamos, Hambridge, Edwards, & Conaghan, 2007). It is possible that earlier recognition of changes, especially mood and behavior changes that impact family functioning may alert people to the need to make changes, such as use of medications, rearranging roles, or altering their methods of communication.

Another possible explanation for why participants with prodromal HD in this study did not attribute changes to HD is because of diminished insight that accompanies brain changes in prodromal HD (Duff et al., 2010). However, the possibility of diminished insight does not explain why companions attributed changes to HD at similar rates, and points to perhaps additional processes at work. Companions of people with HD experienced disruption in their own work and social lives when partners began to have severe symptoms (McCabe, Roberts, & Firth, 2008). They may depend on their partners financially and as co-parents. Thus, denial and normalization are understandable coping strategies for companions as well as people with prodromal HD.

Several participants found it difficult to respond to the Brief COPE because they did not notice changes that significantly interfered with functioning. While all participants were living in the context of prodromal HD, many were also coping with other life stressors, including parenting, extended family issues, finances, and moving. Therefore, some participants may have had these stressors in mind and not necessarily prodromal HD when they responded to the Brief COPE. Participants in this study were also at different family developmental stages—some were recently married without children, some had young children, some had grown children and grandchildren, and some were retired. In the current study, the sample size was too small to explore differences between people at different family developmental stages.

Finally, the couples in this sample may not be representative of most couples living with prodromal HD. For example, the longevity of couples' relationships in this sample was notable. This is a strength in the sense that companions would be more likely to recognize changes in their partners. On the other hand, the longevity of relationships in this study may not be typical of most couples affected by HD.

Participants in this study may also differ from others with prodromal HD because they have been tested for the HD gene expansion while most people at risk for HD still forgo genetic testing (Tibben, 2007). People at risk for HD who predicted they would not cope well with test results may be less likely to undergo testing (Codori, Hanson, & Brandt, 1994). People who do not undergo HD genetic testing have been shown to use more avoidance, self-blame, and wishful thinking than those who do (Pakenham, Goodwin, & MacMillan, 2004). Thus, there may be important differences between how people cope depending on whether they undergo HD genetic testing and whether they participate in research or not.

The results of this study indicate that people with prodromal HD and their companions may cope in unique ways and may provide useful information to assist couples in coping with prodromal HD. Although there is no cure for HD, participants reported effective coping strategies. Participants who used prescription drugs, for example, stated they were effective, particularly for depression, which has been associated with reduced health-related quality of life in people with diagnosed HD (Ho, Gilbert, Mason, Goodman, & Barker, 2009). Couples who used instrumental support, including therapy and seeking information about HD also stated these coping strategies were effective. While neither are cures for HD, they may help people cope with daily life.

Results of this study are also useful to genetic counselors and therapists who see clients considering testing for the HD mutation. It is customary to provide information to people exploring testing. This study indicates that information can be a positive coping strategy for people with prodromal HD and their companions. The counselor/therapist can assess individuals' coping strategies, which may provide insight about their future coping abilities and whether coping is likely to be adaptive and healthy vs. maladaptive and possibly problematic. This may include understanding of how individuals at risk for HD and their companions use denial as either a positive method of coping through normalization, or as a negative method of avoidance when other coping strategies might be more effective. These findings may also be useful for counselors working with couples faced with other neurodegenerative disorders for which genetic testing is available, and which have prodromal or early phases with subtle symptoms, such as Alzheimer disease and Parkinson disease.

While researchers can identify cognitive changes in people with prodromal HD years before onset (Paulsen, 2010), it is still difficult to state definitively that the changes reported by participants in the current study were related to HD. While it was not necessary for participants to attribute changes to HD in order for them to take action to cope with them, participants who did attribute changes to HD used acceptance and self-distraction coping strategies. Therefore, couples may benefit from knowing early changes may be related to HD so they don't try to fix things that cannot be fixed. Acceptance by people with diagnosed HD and their partners of changes was associated with better mental health in two studies (Helder et al., 2002a; Kaptein et al., 2007).

Other research methodologies would be helpful for understanding whether attributing changes to HD influences coping strategies and affects wellbeing. Using wellbeing as an outcome measure, regression analyses might reveal differences in coping strategies between people who attribute changes to HD and those who do not, and illuminate modulating relationships between coping strategies and measures of wellbeing. This strategy would also allow for analysis of dyadic coping by exploring how partners' coping strategies affect wellbeing in each other (Berg & Upchurch, 2007).

There are no data currently that explore whether people with prodromal HD and their companions would like information regarding whether changes they notice might be related to HD. This information might be helpful for making future plans and adjusting roles. For example, in the current study, companions mentioned helping their partners more than they once did. On the other hand, until effective treatments to prevent or delay HD onset are available, there may be risks of informing people that they may be experiencing HD-related changes prior to diagnosis. These may include increased depression and hopelessness, and premature role adjustment. Future studies are necessary to explore perceived risks and benefits of receiving this information from the perspective of people with prodromal HD and their companions.

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Table 1

Sample interview questions

Question	Probes
How are things going at home? Is this a change?	<i>How are you getting along with family members? How are things going with your home projects or hobbies? How about childrearing or housework?</i>
How are things going at work? Is this a change?	<i>How about getting your work done? Getting to work or appointments on time? Interactions with coworkers/supervisors/clients/customers? Enjoying your job as much as you used to?</i>
So, you've noticed that _____ is a change for you. What do you think is the reason for this change?	<i>Why do you think this change has happened?</i>
What have you been doing to cope with this change?	<i>What have you been doing to manage this change?</i>
What can you tell me about how effective this has been in helping you cope with/manage this change?	<i>Has it been working for you? Why do you think it has/hasn't been working for you? What do you think may be a better way to manage this change? Why?</i>

Table 2

Most and least frequently used coping strategies on the Brief COPE

	Prodromal HD		Companions	
	Mean	SD	Mean	SD
Most frequently used coping strategies				
Acceptance	3.29	0.48	3.18	0.90
Emotional support	3.23	0.67	2.56	1.11
Planning	2.92	0.74	2.48	0.78
Least frequently used coping strategies				
Denial	1.20	0.36	1.29	0.45
Substance use	1.39	0.65	1.15	0.53
Behavioral disengagement	1.27	0.39	1.15	0.41

Table 3

Comparison of Quantitative and Qualitative Coping Strategies

Coping Strategy	Brief COPE		Interview	
	Prodromal HD Number (%) who used strategy at least "a little bit"	Companion Number (%) who used strategy at least "a little bit"	Prodromal HD Number (%) who mentioned strategy	Companion Number (%) who mentioned strategy
Emotional support	23 (100%)	17 (74%)	2 (8.7%)	1 (4.3%)
Acceptance	22 (95.7%)	22 (95.7%)	4 (17.4%)	6 (26.1%)
Active coping	22 (95.7%)	20 (87%)	16 (69.6%)	8 (34.8%)
Instrumental support	22 (95.7%)	17 (74%)	12 (52.2%)	2 (8.7%)
Venting	20 (87%)	17 (74%)	3 (13%)	0
Planning	19 (82.6%)	20 (87%)	6 (26.1%)	2 (8.7%)
Positive reframing	19 (82.6%)	19 (82.6%)	1 (4.3%)	1 (4.3%)
Self-distraction	18 (78.3%)	15 (65.2%)	4 (17.4%)	4 (17.4%)
Religion	14 (60.9%)	14 (60.9%)	1 (4.3%)	0
Self-blame	10 (43.5%)	10 (43.5%)	0	0
Humor	9 (39.1%)	9 (39.1%)	2 (8.7%)	0
Behavioral disengagement	5 (21.7%)	7 (30.4%)	5 (21.7%)	4 (17.4%)
Denial	3 (13%)	3 (13%)	0	0
Substance use	3 (13%)	3 (13%)	1(4.3%)	0
Prescription medications	na	na	9 (39.1%)	0
Coping as a couple	na	na	4 (17.4%)	0
Helping partner	na	na	Na	6 (26.1%)
Hope	na	na	4 (17.4%)	1 (4.3%)
Self-monitoring	na	na	4 (17.4%)	na